

Assessing and Documenting Impairment in CFS

Assessment Tools

The following pages offer information on various assessment instruments that can be used in the clinical setting. Some are provided in their entirety; others offer examples of assessment questions and/or access information.

Validated Assessment Instruments

Recommended assessment instruments include the CDC Symptom Inventory (Wagner et al., 2005), SF-36 (Ware and Sherbourne, 1992) and MFI-20 (Smets et al., 1995), which are comprehensive and scientifically validated instruments that provide documentation of the illness. These tools may be considered more appropriate by providers who need a more in-depth assessment. The Multidimensional Fatigue Inventory (MFI) is a 20-question survey that assesses the physical, psychosocial and cognitive impact of fatigue on perceived quality of life over the prior month.

The Visual Analog Pain Scale is a widely accepted and used tool, as are verbal rating scales and the Wong-Baker FACES Pain Rating Scale (Hockenberry et al., 2005).

CDC Symptom Inventory

The CDC Symptom Inventory for clinical application addresses the presence of the eight case-defining CFS symptoms and their magnitude and frequency. A research version contains 21 items, which address the eight case definition symptoms as well as eleven other commonly reported symptoms.

The full-text research study (Wagner et al., 2005) is available online at www.pophealthmetrics.com/content/3/1/8

To download the clinical version of the CDC Symptom Inventory visit www.cfids.org/treatcfs/CDCSI.pdf

For additional information on the research version contact meded@cfids.org

SF-36 Health Assessment Tool

Ware JE Jr, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care* 1992 Jun;30(6):473-83.

The SF-36 (for information, visit www.sf-36.org) is a multi-purpose, short-form health survey with only 36 questions. It yields an 8-scale profile of functional health and well-being scores as well as psychometrically-based physical and mental health summary measures and a preference-based health utility index. It is a generic measure, as opposed to one that targets a specific age, disease or treatment group. The item is available for clinical and academic use as the Rand-36 and is available at:

Rand Health website: Retrieved October 20, 2006 from the Rand Health website:
www.rand.org/health/surveys_tools/mos/mos_core_36item.html

Questionnaire: Retrieved October 20, 2006 from the Rand Health website:
www.rand.org/health/surveys_tools/mos/mos_core_36item_survey.html

Scoring rules: Retrieved October 20, 2006 from the Rand Health website:
www.rand.org/health/surveys_tools/mos/mos_core_36item_scoring.html

Multidimensional Fatigue Inventory (MFI-20)

Smets EMA, Garssen B, Bonke B, De Haes JCJM. The multidimensional fatigue inventory (MFI) psychometric qualities of an instrument to assess fatigue. *J Psychol Res* 1995;39(5):315-25.

The Multidimensional Fatigue Inventory (MFI-20) is a 20-item self-report instrument consisting of five scales: General Fatigue, Physical Fatigue, Reduced Activity, Reduced Motivation, and Mental Fatigue. Each scale contains four items rated on a scale of zero to 5 with the scale score of zero having the anchor of entirely true and the scale score of 5 having the anchor of no, not true. The five scales were identified through factor analysis and are assumed to measure different aspects of fatigue. For information on acquiring the MFI-20, contact meded@cfids.org

A brief excerpt from the MFI-20:

I feel tired	yes, that is true	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	no, that is not true
I think I do a lot in a day	yes, that is true	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	no, that is not true
When I am doing something, I can keep my thoughts on it	yes, that is true	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	no, that is not true
Physically I can take on a lot	yes, that is true	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	no, that is not true

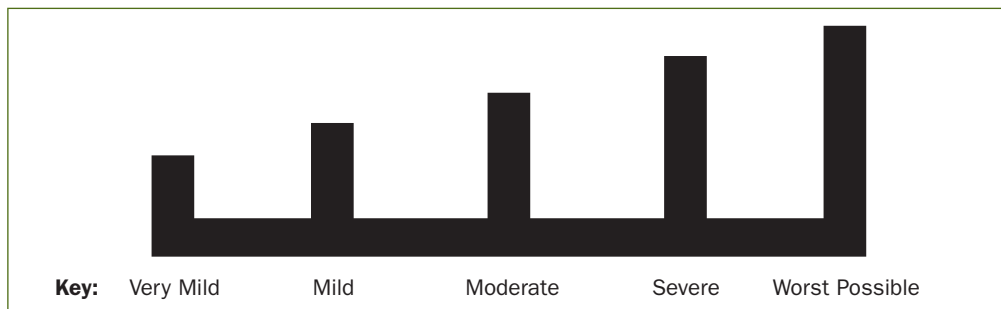
Scales

Visual Analog Scale

None		Mild		Moderate		Severe		Worst possible	
0	1	2	3	4	5	6	7	8	9 10

Verbal Pain Scale

Describes the degree of discomfort by choosing the vertical lines that best correspond to symptom intensity.



The Wong-Baker Faces Pain Rating Scale

Designed for children aged 3 years and older, the Wong-Baker Faces Pain Rating Scale is also helpful for people who may be cognitively impaired, the elderly or those with a language barrier. It offers a visual description rather than verbal.



Hockenberry M, Wilson D, Winkelstein ML. *Wong's Essentials of Pediatric Nursing*, ed. 7, St. Louis, 2005, p. 1259. Used with permission. Copyrighted by Mosby, Inc.

Other validated assessment tools assess specific symptoms such as sleep problems or depression. Examples are as follows:

Beck Depression Inventory

The original, scientifically validated Beck Depression Inventory tool was developed in 1961. An updated version of the tool was created in 1996 to better reflect DSM-IV criteria (Beck Depression Inventory® -II)(BDI® -II, Beck AT, Steer RA, Brown GA).

The BDI-II consists of 21 items to assess the intensity of depression in clinical and normal patients. Each item is a list of four statements arranged in increasing severity about a particular symptom of depression. Example questions:

- | | |
|---|---|
| <input type="radio"/> I do not feel disappointed in myself. | <input type="radio"/> I do not feel sad. |
| <input type="radio"/> I am disappointed in myself. | <input type="radio"/> I feel sad. |
| <input type="radio"/> I am disgusted with myself. | <input type="radio"/> I am sad all the time and I can't snap out of it. |
| <input type="radio"/> I hate myself. | <input type="radio"/> I am so sad or unhappy that I can't stand it. |

The instrument can be ordered from the Harcourt Assessment website, <http://harcourtassessment.com/haiweb/cultures/en-us/productdetail.htm?pid=015-8018-370>

PHQ-9

The PHQ-9 is a validated assessment instrument comprised of the nine signs and symptoms of depression in the DSM-IV with a question on functional impairment from the symptoms (as also required in the DSM-IV). The MacArthur Foundation Initiative on Depression and Primary Care has created a Depression Tool Kit, which is intended to help primary care clinicians recognize and manage depression. The Tool Kit includes easy-to-use instruments and information sources and is free of charge. The kit is available at www.depression-primarycare.org/clinicians/toolkits/materials/forms/phq9/

Pittsburg Sleep Quality Index

The Pittsburg Sleep Quality Index (PSQI) is a reliable and validated self-rated questionnaire that provides an index of sleep quality. The PSQI includes 19 self-rated questions, which are grouped into seven component scores. The research article describing this tool is available at www.sciencedirect.com

Useful Clinical Tools

There are a few brief screening instruments that can help monitor a patient's functional status and eligibility for disability benefits. Although not scientifically validated, these tools were designed by practitioners for ease of use in the clinical setting to help document status from visit to visit. Bell's Disability Scale provides a numerical representation of an individual's severity of symptoms, degree of activity impairment and ability to function in full-time work (Bell, 1995). The Subjective Functional Capacity Assessment (Lapp, 1993) is a helpful measure of the functional impact of fatigue.

Bell's CFS Disability Scale

This scale is from The Doctor's Guide to Chronic Fatigue Syndrome, by David S. Bell, MD, pages 122-123. Addison-Wesley Publishing Company, Reading, MA. Copyright © 1994, 1995.

The attempt is to document as accurately as possible the severity of symptoms, the degree of activity impairment with both activity and rest, and the functional ability regarding full-time work.

- 100** No symptoms at rest. No symptoms with exercise; normal overall activity level; able to work full-time without difficulty.
- 90** No symptoms at rest; mild symptoms with activity; normal overall activity level; able to work full-time without difficulty.
- 80** Mild symptoms at rest, symptoms worsened by exertion; minimal activity restriction noted for activities requiring exertion only; able to work full-time with difficulty in jobs requiring exertion.
- 70** Mild symptoms at rest; some daily activity limitation clearly noted. Overall functioning close to 90% of expected except for activities requiring exertion. Able to work full-time with difficulty.
- 60** Mild to moderate symptoms at rest; daily activity limitation clearly noted. Overall functioning 70%–90%. Unable to work full-time in jobs requiring physical labor, but able to work full-time in light activities if hours flexible.
- 50** Moderate symptoms at rest; moderate to severe symptoms with exercise or activity; overall activity level reduced to 70% of expected. Unable to perform strenuous duties, but able to perform light duty or deskwork 4–5 hours a day, but requires rest periods.
- 40** Moderate symptoms at rest. Moderate to severe symptoms with exercise or activity; overall activity level reduced to 50%–70% of expected. Not confined to house. Unable to perform strenuous duties; able to perform light duty or deskwork 3–4 hours a day, but requires rest periods.
- 30** Moderate to severe symptoms at rest. Severe symptoms with any exercise; overall activity level reduced to 50% of expected. Usually confined to house. Unable to perform any strenuous tasks. Able to perform deskwork 2–3 hours a day but requires rest periods.
- 20** Moderate to severe symptoms at rest. Severe symptoms with any exercise; overall activity level reduced to 30%–50% of expected. Unable to leave house except rarely; confined to bed most of day; unable to concentrate for more than 1 hour a day.
- 10** Severe symptoms at rest; bedridden the majority of the time. No travel outside of the house. Marked cognitive symptoms preventing concentration.
- 0** Severe symptoms on a continuous basis; bedridden constantly; unable to care for self.

Subjective Functional Capacity Assessment Tool

Name _____ Date _____

Please circle the best response for each activity described below:

Activities of Daily Living

(e.g., bathing, dressing, feeding self, toilet)

1. Need some assistance
2. Slight difficulty
3. Minimal difficulty
4. No problem

Laundry

1. Unable
2. Occasionally
3. Regularly in small steps or with help
4. Regularly without help

Cooking

1. Unable
2. Take out; simple breakfast or lunch only
3. Simple microwave or crock-pot meals
4. Regular meal preparation

Housekeeping

1. Unable
2. Light dusting, "neaten up"
3. Regular chores: small steps or with help
4. Regular

Grocery Shopping

1. Unable
2. Occasionally (once or twice/month)
3. Frequently, but with assistance
4. No problem

Social Activities

(e.g., religious services, meetings, family, friends)

1. Unable
2. Infrequently
3. Occasionally (once or twice/month)
4. Frequently (one or more times/month)

Driving

1. Unable
2. Rarely
3. Cautious, local trips
4. Distant trips or traffic

Errands or Light Chores

(e.g., convenience store, post office, drop off child)

1. None
2. 0-1 per day
3. 1-2 per day
4. Few restrictions

Please indicate for how long you can perform the following activities on a typical day:

(Total amount of time each day, with rest periods as necessary)

	Not at all	15 minutes	30 minutes	1 hour	1-3 hours	> 3 hours
Sedentary (sitting, watching TV)	1	2	3	4	5	6
Light activity (eating, small crafts)	1	2	3	4	5	6
Moderate activity (tidy room, fix meal)	1	2	3	4	5	6
Heavy activity (vacuum room, rake yard)	1	2	3	4	5	6

Source: Charles W. Lapp, MD, Hunter-Hopkins Center, Charlotte, NC

Brief Sleep Questionnaire

Developed by J.F. Jones, MD for clinical practice.

This simple questionnaire can be used by health care clinicians to quickly assess sleep status and pinpoint potential problem areas:

1. Do you have trouble falling asleep?
2. What time do you go to bed?
3. What time do you go to sleep?
4. Do you read or watch TV in bed for longer than 15 minutes?
5. Is your sleep restless (are sheets very disturbed upon awakening)?
6. Do you snore?
7. What time do you awaken?
8. What time do you get up for the day?
9. Do you feel rested upon awakening?
10. Do you sleep in the daytime or during your normal awake hours?

CFS and Disability

By definition, all people with chronic fatigue syndrome (CFS) are functionally impaired, and studies have shown that approximately one-third of these people are unable to maintain full-time employment after becoming ill. Some are able to continue to work full time; some are able to work only part time; and numerous others are unable to work at all.

Work is a source of identity and self-esteem for many people, and the inability to work can have negative health consequences. Some people have difficulty accepting that they may have to discontinue working and rely upon insurance companies, government or family for financial support. People grieve the loss of independence, financial security, self-sufficiency, social connectedness and sense of productivity that come with employment.

The application process for disability benefits is often protracted and frustrating. In order to demonstrate their need for benefits, applicants must identify all the things they are now incapable of doing. Admitting their weaknesses and limitations can be emotionally difficult. Completing the application forms and gathering the information necessary to justify their application is a physically, cognitively and mentally draining process. Many applicants may choose to hire an attorney or rely on the assistance of a trusted family member or friend to help them through the process. If your patient is represented by an attorney in disability matters, it is advisable to obtain a release form from the patient allowing you to communicate with the attorney.

Documentation Fundamentals

Treating health care professionals are a major source of pertinent information required for the disability application. All members of the health care team can contribute useful information. For example, referrals to rehabilitation and physical therapists can provide constructive approaches that maximize medical improvement and assist with disability

documentation. Information from relatives, friends, counselors, therapists and others can be used to illustrate the severity and nature of the patient's impairments, as long as they are recorded by the treating physician and the information is justifiable and credible. Also, the patient or family may be able to provide a diary or summary of typical daily activities. Patients' journals are also considered pertinent evidence.

It is helpful to record supportive medical signs such as swollen or tender lymph nodes, pharyngitis and persistent reproducible muscle tenderness (e.g., the tender points of fibromyalgia). Abnormalities in MRI, orthostatic dysfunction by tilt-table testing, abnormal sleep studies, mental status or neuropsychiatric testing or functional capacity examinations can support functional impairment.

The process of preparing letters or reports or filling out forms can be time-consuming, but may be streamlined by maintaining adequate documentation, keeping detailed office notes and following an outline. Documentation needs to be as complete and specific as possible.

Documentation of Impairment

Impairments might include increased fatigue with physical or mental exertion (limits ability to function on a regular and sustained basis), pain (reduces mobility) and difficulty with concentration, comprehension of new information, recall or memory tasks and executive function (making calculations, handling money) or difficulty in driving. These may be documented by contemporaneous office notes detailing symptoms, treatments and how these impairments impact the patient's activities of daily living and work. Next, it is necessary to establish that these impairments prevent even sedentary and light activities on a regular, predictable or sustained basis. Lastly, the health care professional must generally predict, based on experience and the patient's response to therapy, how long impairments would be expected to last.

Social Security and Long-Term Disability

Social Security Ruling 96-8p and SSA Forms 4734-U8 and 4734-F4-SUP provide information on functional impairment.

Social Security Benefits

The *Social Security Act* definition of “disability” poses three medical questions:

- 1) Is there a medically determinable impairment (or combination of impairments)?
- 2) Does it significantly limit the person’s physical and/or mental ability to perform substantial gainful work?
- 3) Is it expected to last a continuous period of at least 12 months (including any past period of incapacity) or result in death?

The Social Security Administration (SSA) has issued policy guidance for CFS claims. Social Security Ruling 99-2p states that CFS can be a disabling condition and people who meet SSA’s criteria for disability are eligible for benefits (Social Security Administration, 1999).

Reports to SSA must include a description of the person’s functional status and highlight any clinical findings. SSR 99-2p outlines the criteria by which CFS can be defined as a medically determinable impairment. Examples include: neurocognitive impairment documented by mental status examination or psychological testing; anxiety or depression; persistent, reproducible muscle tenderness, including positive tender points; an abnormal exercise stress test; abnormal sleep studies; elevated antibodies to Epstein-Barr virus (EBV); an abnormal magnetic resonance imaging brain scan; swollen or tender lymph nodes; nonexudative pharyngitis; neurally mediated hypotension; or any other medical signs or laboratory findings that are consistent with medically accepted clinical practice and are consistent with the other evidence in the case record. Once a medically determinable impairment is documented, patients still must prove

that they are functionally impaired to the degree that they are unable to work at any job available in the local economy.

SSA requires that benefits are awarded to people whose conditions meet or equal the criteria for any of the disabilities that SSA includes in its official *Listing of Impairments* (Social Security Administration, 2003). CFS is not a “listed” condition. However, CFS patients have also been awarded SSA benefits because their symptoms meet criteria for other listed conditions, even though properly documented and disabling CFS can meet criteria on its own.

Long-Term Disability Benefits

Many people with CFS are also eligible for long-term disability (LTD) insurance benefits through an employer-provided or individual policy. It is crucial for the health care professional to discriminate between disability caused by a patient’s CFS symptoms and primary mental health conditions, particularly if the patient has access to LTD benefits. Since LTD policies typically limit benefits to 24 months for people disabled by mental health conditions, it is possible that benefits will be prematurely terminated for people disabled by CFS who have: 1) been incorrectly diagnosed with a primary mental health disorder, or 2) have been diagnosed with a secondary mental health disorder and the clinician’s office notes do not clearly show that the mental health condition is secondary to the effects of CFS.

Other Financial Supports

People with CFS may benefit from other social assistance programs offered through the government or community agencies. These may include medication discounts, food stamps, Supplemental Security Income from SSA, home health care assistance, help with paying utility or other bills, etc. Social workers and Centers for Independent Living are helpful sources of information about local programs for which people with CFS may be eligible.

Additional Information/Resources

Disability Evaluation Under Social Security (also known as the Blue Book; 187 pages)

Retrieved October 11, 2006 from Social Security Administration website:
www.socialsecurity.gov/disability/professionals/bluebook/index.htm

Disability Evaluation Under Social Security Blue Book General Information; 13 pages

Retrieved October 11, 2006 from Social Security Administration website:
www.socialsecurity.gov/disability/professionals/bluebook/general-info.htm

Evidentiary Requirements for Medical Professionals Under Social Security Blue Book

Retrieved October 11, 2006 from Social Security administration website:
www.socialsecurity.gov/disability/professionals/bluebook/evidentiary.htm

Disability Evaluation in a Nutshell: A Three-Minute Guide to Effective Medical Reports

This 16-page booklet includes SSA listing of impairments (adult categories), an example of a hypothetical medical professional's report and a "doctor's checklist for functional impairment." Retrieved October 11, 2006 from CFIDS Association of America website: www.cfids.org/ecommerce/products.asp?setCategory=21

Physicians Disability Service (PDS): This attorney-developed website offers materials on various disability issues.

Retrieved October 11, 2006 from Physicians Disability Service website: www.disabilityfacts.com

American Academy of Disability Evaluating Physicians

Activities include: 1) ongoing teaching of the management of disabled patients; 2) teaching impairment and disability evaluation to physicians, other health care providers, attorneys, regulators, legislators and others involved in the care of the disabled; and 3) coordination of research in the area of disability management. Retrieved October 11, 2006 from American Academy of Disability Evaluating Physicians' website: www.aadep.org

The CFS Empowerment Project is a federally funded demonstration project that uses occupational therapy methods to improve patient quality of life. Retrieved October 11, 2006 from the CFS Empowerment Project website:

www.ahs.uic.edu/ahs/files/ot/bookler/CFS_Website/index.htm

References — Appendix A

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A note about Internet-based resources: As the Internet is ever-changing, it is not possible to ensure that each website listed within the course remains operational and contains the precise information as retrieved by the course developers. All information is current as of October 20, 2006.